

MINUTES OF THE
JOINT HEALTH AND HUMAN SERVICES APPROPRIATION SUBCOMMITTEE
Friday, February 2, 2001
State Office Building Auditorium

Members Present: Sen. David H. Steele, Committee Co-Chair
Rep. Jack A. Seitz, Committee Co-Chair
Sen. Edgar Allen
Sen. Curtis S. Bramble
Sen. L. Steven Poulton
Rep. Trisha Beck
Rep. David L. Hogue
Rep. David Litvack
Rep. Rebecca Lockhart
Rep. Carl S. Saunders
Rep. Matt Throckmorton

Staff Present: Thor Nilsen, Legislative Fiscal Analyst
Spencer C. Pratt Legislative Fiscal Analyst
Norda Shepard, Secretary

Public Speakers Present: Robin Arnold-Williams, Executive Director, Department of Human Services
Sue Geary, Director, Division of Services for People with Disabilities
Pheobe Blackham, State Family Council
Pete Shingledecker, Legislative Coalition for People with Disabilities
Jerry Costley, ARC of Utah
Dolores Vawdrey, President ARC of Utah
John Harbert, Utah Association of Community Services
Carola Zitzman, Utah Health Care Association
Mary Sutton
Todd Barrett
RaeAnn Barrett
Shawn Delobel
Jerrie Hofeling
Barbara Toomer
Steve Johnson
Kendra Burton
Sarah Burton
Boyd Twiggs
Carol Edic
Udell Blackham
Cynthia Everitt
Shane Sadler
Amy Hines
Florence Vooheers

Visitor List on File

Committee Co-Chair Seitz called the meeting to order at 2:00 p.m.

1. Budget Hearing: Division of Services for People with Disabilities

Analyst Thor Nilsen stated that this is the largest division in the Department of Human Services, with a recommended budget of just over \$133 million, including \$40.3 million from the General Fund. The division is responsible for providing residential, day and family support services for people with mental retardation and other developmental disabilities. The analyst is recommending, in accordance with intent language, replacing the increase in TANF funds of \$1,500,000. Mr. Nilsen reported there are about 1,900 people in immediate need of services on the waiting list. The analyst is recommending consideration be made, if funds become available, to provide another \$1.75 million in General Funds for next year for people on the waiting list. He discussed the intent language found in the Budget Analysis book for this division, highlighting the Lisa P. settlement and the waiting list, both of which will be reported on by the division. He is recommending that intent language item "f." on Page 8 be taken out. The Budget Analysis book also contains graphs showing performance and outcome measures for committee information.

Robin Arnold-Williams, Executive Director, Department of Human Services, introduced Sue Geary, Director, Division of Services for People with Disabilities. The division distributed printed information which Ms. Geary discussed. The handout contained information on whom the division serves, what services they offer, the expenditures per person, the number of people being served, the number on the waiting list and the annual budget. It also contained a chart with a three year comparison of the waiting list, a report of action taken as a result of intent language, and a detailed list of the division's FY2002 budget requests.

Pheobe Blackham, State Family Council, distributed and discussed a report on the urgent need to fund the critical needs waiting list. She stated the council is reaching out to help support those on the waiting list who have absolutely no support at this time. She discussed the \$500 grant allocation given to 1,200 people on the list and stated the pie chart on her handout showed the use of these grant funds. She stated she was speaking for these people on the waiting list but also for their families whose energies are often consumed in meeting the day-to-day- needs of their loved ones. She stated the Family Councils are doing all that can, that they believe the Division is doing all that they can, and they now need the committee to do all it can by fully funding the waiting list this year.

2. Approval of Minutes

MOTION: Rep. Saunders moved to approve the minutes of 1-31-01. The motion passed unanimously with Sen. Poulton, Rep. Lockhart and Rep. Throckmorton absent at the time of voting.

3. Voting on Department of Health Budgets

MOTION: Rep. Hogue moved to consider for the priority list the Division of Epidemiology and Laboratory Services, the Division of Community and Family Health Services, and the appropriation request for Sexual Violence Prevention and Community Awareness. The motion passed unanimously with Sen. Poulton absent at the time of voting.

4. Pete Shingledecker, Legislative Coalition for People with Disabilities

Mr. Shingledecker expressed thanks for being allowed to speak to the committee and thanked the analysts and members of the committee who work so hard to learn and understanding the system. He stated these efforts greatly impact the lives of many people. He distributed a fact sheet which detailed a plan to fund needed services for people with disabilities in Utah. He also handed out a pamphlet "Dreams are for Everyone" which describes how the Utah Family Councils can help the disabled. He stated the plan is also supported by The Arc of Utah, United Cerebral Palsy, and the Utah Association of Community Services. He stated he would like the committee to meet a few people whose lives will be dramatically affected by the decisions the committee will

make.

Mary Sutton stated she has progressive Multiple Sclerosis. She is legally blind, confined to a wheelchair, and cannot not do many things that she once could do. She said her husband is overwhelmed by trying to provide for the family, take care of her and do all that she used to do. She stated she needs help with grooming, housework and meals. She has been on the waiting list for one and a half years.

Todd Barrett said he was glad to be here. His mother, RaeAnn Barrett, said Todd has had many different problems since birth and about eight years ago he was also diagnosed with T-cell anemia and now with sleep apnea. He has been hospitalized 26 times. She stated Todd is the third of five children and he has watched his siblings do the things he cannot do and progress and move on. He has been on the waiting list since he was 16. He is now 27 years old and asks every day when he can go into a group home. She said it is frustrating as a parent to try and explain why he has to wait. She challenged the committee members to look around the room and see all the people who need help and to reach out and support additional funding to help them.

Shawn Delobel stated his daughter Katlyn, who was born with a brain disorder, has been on the waiting list since she was about seven months old and is now five. He said he wanted to address how families make it without the funds. He said Katlyn requires 24 hour care, so his wife cannot work. He works two jobs, sometimes three when possible. He also does side jobs in between and goes to his church for help when difficult times require it. They ask help from friends, family members, and relatives. He said that services to them would mean that his wife could have more time for her children, she could leave the house by herself and have a break, and maybe he could cut down one job and spend more time with his family. He said his biggest fear is that Katlyn will not live to make it off the waiting list. He said he understands the job before the committee is incredible and that there are many in need like his family. He said most just want a chance.

Mr. Shingledecker thanked the committee for listening. He stated that nothing can compare a family for the arrival of a child with severe disabilities. Often times the child's needs can be overwhelming even for the strongest families. He stated that 1,900 people have called out for help and been told to wait. He stated that providing support for people with disabilities is a delicate balance of government agencies, private providers, and natural support systems. Utah has developed a strong network and system of qualified professionals who dedicate their lives to people with disabilities. However, we are at a point when this delicate balance must be strengthened. He said we must act now to provide a COLA and \$17.9 million in state funds to meet the needs of our systems and completely eliminate the waiting list.

5. Jerry Costley, ARC of Utah

Jerry Costley, Executive Director, introduced Dolores Vawdrey, President of ARC of Utah, who stated she is not only a very active volunteer but also is the mother of a son with mental retardation. She said she came from a very strong family and thought they could handle anything and succeed, but she found that having a child with disabilities affects the whole family. It puts a strain on even the strongest marriage. If a family does not have support and tries to do it all themselves with no breaks, it can be a difficult struggle. She said it is not just the 1,900 people on the waiting list who need help but their parents and siblings make this number much higher. She asked if asking for increased funding of 6% was asking too much.

Mr. Costly stated his organization represents persons with mental retardation and related disabilities and their families throughout the state. He said that historically we haven't always had a waiting list but it has been growing steadily over the past several years at about 100 individuals a year in spite of the efforts that have been made. He said they would like to express gratitude for funds that have been made available in the past. These funds have prevented the list from growing completely out of control. He said that the problems of people on the waiting list tend to grow worse and get more expensive and difficult as time goes on. He said in terms of investing, it is not investing very wisely when we make people wait until those services become extremely

expensive. He said that funding the waiting list is doable. It is a matter of priorities and where we place them.

Sen. Steele explained the funding process. He stated that this committee is not the only appropriation committee meeting and discussing funding. This budget is only a part of the overall state budget. He said the committee will do its best to meet the needs put before it, but all these concerns will need additional support from Executive Appropriations consideration and leadership consideration. He encouraged people to share their concerns with these entities well before the legislature meets.

6. John Harbert, Utah Association of Community Services (UACS)

Mr. Harbert distributed a printed letter outlining the concerns of the Utah Association of Community Services. He indicated they have two main concerns; the amount of money paid to staff and turnover of the staff. He said they support the recommendation to fund a cost of living adjustment to private providers of at least 6%. He stated they have empathy for families in the system who don't know when or if services will ever arrive. They may be near the head of the list when someone with a more critical need comes and takes their place.

Jerri Hofeling said her 25 year old son, Ryan, has been fortunate to be in a group home for the past ten years. Prior to that he was receiving services at the Developmental Center. She said she appreciates the funding that has come to allow him to participate in the group home. She said in an attempt to illustrate the need for the COLA request, she would like the committee to consider how it would feel to have one half of your family go away and be replaced with people you do not know. She said the cost of living adjustment is very important in order to guarantee consistency in provider's staffing.

Chair Seitz explained that this committee does not control the COLA or the wage consideration. That is handled by Executive Appropriations. He stated the Co-chairs have already made a request that they consider this COLA increase.

Misty Samuels, an employee of Community Treatment Alternatives, stated she works in a group home and the turn over causes turmoil, not only for the residents, but also for the staff members. She stated it would definitely help to have the COLA increase.

Rep. Litvack stated he had the opportunity to visit one of the group homes and gained a greater appreciation, not only for the people who lived there, but for the staff. He said the staff was very well trained. He felt it was a wonderful experience to be able to visit and wanted to share this experience with the committee.

7. Carola Zitzman, Utah Health Care Association

Carola Zitzman stated she was staff to the Utah Health Care Association and represents care facilities for the mental retarded, whose budget will be heard next week. She is also a parent of a son in the program in Ogden, but she stated she was here today to support John Harbert's position on the COLA. After the discussion she said she wanted the committee to know that the association supports their request and hopes that it will be requested in the Executive Appropriations Committee.

8. Other Public Testimony

Chair Seitz invited public testimony.

Barbara Toomer, ADAPT Utah, said she was representing nursing homes. She pointed out that not just older people are in nursing homes but there are a lot of young people with disabilities there also. She distributed a handout entitled "Our Homes Not Nursing Homes" which outlined the ruling made by the courts that when a disabled individual can live in the community and can be served effectively that person must be given the choice

to do so. She stated the Ohlmstead Act stated there must be a comprehensive, effective working state plan to address this, which Utah will have in place in June.

Steve Johnson stated he represents the "Our Homes Not Nursing Homes" project. He said their basic purpose is to meet and talk with nursing home occupants informing them of available waivers and helping them, if they are able, to live outside the nursing home. They work also to try to get resources so they can return into their own communities. He passed out copies of a newspaper article entitled "A home at last for Christmas" which told the story of three individuals who were able to leave the nursing home setting into group homes or apartments. He said allowing these individuals this choice makes financial sense and demonstrates wisdom.

Kendra Burton said she would like to commend the valiant people in the room. She introduced her nine year old twin daughters, Sarah who was born healthy, and Rachel, born with hydrocephalus. She stated that while Sarah will move on and become a contributing member of society, Rachel will be at home and be cared for by her family for the rest of her life. Rachel was on the waiting list for three years. She said that three years may sound short, but when you have a disabled child, it seems like an eternity. She expressed gratitude that they will be able to receive help. She distributed a poem entitled "Dreams" and stated the Sarah would sing the song as the voice of her sister, Rachel, who cannot speak. Mrs. Burton and Sarah sang the song together. Mrs. Burton said she appreciated the time given to her and she hoped the committee could increase funding to help other families.

Boyd Twiggs from the Mental Retardation Association of Utah told the story of a man who purchased an inexpensive screwdriver to perform a minor repair job, but half way through the job, the screwdriver broke, which made him think that the bitterness of poor quality remains long after the sweetness of the cheap price. Mr. Twiggs stated that is the problem we will have if we don't take care of the waiting list and needs become more critical.

Carol Edic, passed around pictures of her son, Paul, who has cerebral palsy. She said she would speak to the question of what happens to people when they don't get services. He currently is living at South Davis Community Hospital in Bountiful because her health gave out after caring for him all by herself for 20 years. She told of an experience she had when she became too ill to care for her son and had difficulty getting a place for her son to go. She passed out a printed letter to the committee.

Udell Blackham said he was here as a dad. He asked that the committee keep a couple of things in mind. He said we can avoid high care costs by funding things early. He stated that though it might seem easier to defer, the longer we defer the greater the problem becomes. The second point he asked to keep in mind is that every dollar you can appropriate to fund the waiting list has the impact of affecting more families, because the needs become less critical and therefore the dollars can go further.

Cynthia Everitt stated she is a parent who felt she had to move her son out of Utah. Her son is 25 years old and had been on the waiting list more than ten years. She stated the waiting list did not move and gave her no choices, no freedoms, and no hope. She felt her son was trapped so she moved him to California where he is doing well and living the life he wants in a group home. She said her family has been splintered so a future could be made for her son that couldn't be made in Utah.

Shane Sadler displayed a picture of his son, Harrison. Harrison will be five in March and about two years ago was diagnosed with Autism. He has been on the waiting list for two years. Private insurance will not cover Autism. He stated they have no family support. He stated his wife does a lot of in-home therapy for their son and he attends The Carmen B. Pingree School for Children for Autism. He stated that sometimes we provide ways for people who go into bankruptcy and into crime to get out of that, but sometimes fail to provide for those who are really in need. The big difference is those people made those choices that bring them to bankruptcy or into crime, but people with disabilities did not have a choice. Most of them were born with that disability. The

sooner they can get help, the better off they and their families will be.

Amy Hines is wheelchair bound and has difficulty speaking, but wanted to testify. She said she was glad for the help she received from the programs.

Florence Vooheers, whose son was injured while serving an LDS mission in Argentina, said their family is very fortunate in being able to have family support services. The cost of keeping her son in a nursing home would be astronomical but with family support services he can be kept at home. She said the need for respite for the family is very important and they are grateful for the support they receive. She stated she knows there are many other families who need this help also.

9. Other Committee Business

Rep. Throckmorton stated that this committee hears about these issues every year and that it was time to do something about it. Rep. Hogue said he agreed and felt we have an obligation as a state to take care of those who are less fortunate. Sen. Allen said he was touched by the comment that we have this problem despite good economical times. He said we needed to get out of crisis management as opposed to dealing with things in advance. Rep. Beck stated the state believes in being cost effective and we should put in the funds before we have a major crisis. Sen. Steele said we have been using the band-aid approach and that approach is not the right way to go because band-aids don't stick very well. He stated the co-chairs will be the voice of this committee in the Executive Appropriations and they will echo what has been said here. He said a long term strategy needs to be developed as it has been for education and other state needs.

MOTION: Rep. Saunders moved to adjourn. The motion passed unanimously with Sen. Poulton absent at the time of voting.

Co-Chair Seitz adjourned the meeting at 4:50 p.m.

Minutes reported by Norda Shepard, Secretary.

Sen. David H. Steele
Committee Co-Chair

Rep. Jack A. Seitz
Committee Co-Chair